

# *Privacy And Public Health*

Hearings on the Population Health Dimension

National Health Information Infrastructure Workgroup

National Committee on Vital And Health Statistics

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# *Introduction*

**Public health and privacy principles  
are at a critical intersection**

- Public health activities are increasingly prominent and increasingly essential
- Public health activities depend upon individual health data

# *Introduction*

- Better technical capacity to access health data
- Increased need for public health authorities to exchange data with other parties
- Heightened sensitivity to privacy of health information under federal and state law

# *Introduction*

**Public health activities are increasingly prominent and increasingly essential**

- Bioterrorism
- West Nile virus
- SARS

# *Introduction*

## **Public health activities depend upon health data**

- Communicable disease reporting
- Population health assessment
  - Epidemiological investigation
  - Registries
  - Research
  - Laboratories

# *Introduction*

- Licensure and certification
- Early detection and intervention
- Vital records
- Preventing or controlling disease, injury or disability

# *Introduction*

## **Better technical capacity to access health data**

- Syndromic surveillance
- Improved electronic linkages with providers and local health departments, CDC

# *Introduction*

**Increased need for public health authorities to exchange data with other parties**

- Third-party researchers
- Service providers
- Law enforcement

# *Introduction*

- Community-based organizations
- Other government agencies

# *Introduction*

**Heightened sensitivity to privacy of health information under federal and state law**

- HIPAA

# *Introduction*

- In Illinois, numerous state law protections as well
  - Communicable Disease Code
  - HIV/AIDS, STD

# *Introduction*

- Mental health records
- Medical studies
- Registries

# *Introduction*

- Facilities licensure laws
- FOIA
- Vital records

# *HIPAA Approach*

**The Privacy Rule allows for continued government/public health access to individual health information without authorization or consent**

- Required by law

# *HIPAA Approach*

- Public health activities
- Health oversight

# *HIPAA Approach*

- Avert a serious threat to health or safety
- Disaster relief

# *HIPAA Approach*

## **Required by law**

- Communicable disease reporting
- Mandated lab testing

# *HIPAA Approach*

- Mandated access for licensure/certification
- Vital records

# *HIPAA Approach*

- Special requirements for mandated disclosures regarding victims of abuse, neglect or domestic violence; disclosures for judicial and administrative proceedings; and disclosures for law enforcement purposes

# *HIPAA Approach*

## **Disclosures for public health activities to a “public health authority”**

- “Public health authority”: a government agency, or a person or entity acting under grant of authority from or contract with such agency, authorized by law to collect or receive information for the purpose of controlling or preventing disease

# *HIPAA Approach*

- Includes reporting of disease, injury, vital events; public health investigations and interventions

# *HIPAA Approach*

## **For Health Oversight**

- “Health oversight agency”:  
government agency, or third party acting under grant of authority or contract with such agency, authorized by law to oversee healthcare system

# *HIPAA Approach*

- Includes audits; civil, criminal or administrative investigations, proceedings or actions; inspections; licensure or disciplinary actions

# *HIPAA Approach*

## **HIPAA constraints on public health activities**

- A function of activities

# *HIPAA Approach*

- In Illinois, IDPH a “hybrid entity”
- Blood lead screening, ADAP programs are covered functions
- Adopting a “culture of privacy”, but HIPAA requirements legally mandated only for covered functions

# *Key Issues*

- 1. Possible reductions in reporting to public health authorities due to HIPAA misperceptions**
  - Work aggressively to dispel misperceptions (letters, meetings with community, education)

## *Key Issues*

- Reasonable reliance on a public official's determination that the information requested is the minimum necessary
- Accounting requirements can be a general statement as to the nature of public health reporting

## *Key Issues*

**2. Facilitate innovative but appropriate data relationships between public health authorities and third parties**

- HIPAA maybe more flexible than some state laws

# *Key Issues*

- Research, early intervention, outreach, data processing
- Agency arrangements, contractual arrangements, with confidentiality protections; should be standardized to the extent possible (i.e., designation as a “public health authority”)
- Public health data’s value is in its use

## *Key Issues*

3. **Should focus on reporting to law enforcement, bioterrorism-related investigative activities**
  - Forensic epidemiology generating attention
  - State laws may be inflexible
  - Need for continued state legislative attention and dialogue

## *Key Issues*

- 4. Consider increased pressure for specific health information from the media and the public**
  - For example, West Nile, SARS, cancer statistics

## *Key Issues*

- Protection of public safety vs. protection of privacy
- FOIA laws should be examined
- Litigators, organized labor
- Public health system should strive for consistency in level of detail